Registry Standards of Excellence in Support of an Immunization Program
American Immunization Registry Association (AIRA)

Introduction and Background

The growing literature on immunization registries highlights the benefits and cost-benefits of registries to health care providers, Managed Care Organizations, payors, schools, and health departments. However, little can be found to highlight how registries can support the rest of a state or local immunization program.

In 2001, CDC sought to remedy this by identifying standards and best practices by which an immunization project could more closely integrate its registry functions into their other program components. The CDC contracted with the American Immunization Registry Association (AIRA) to develop these standards. The results are contained in the following pages.

The recommendations and standards are organized according to the Immunization Program Operations Manual (IPOM), a companion resource guide for projects that receive Section 317 funds. IPOM was first developed in 1997 by CDC with immunization project input, and subsequently updated in 2000. This manual lists a range of activities that make for an excellent immunization program. As such, it was seen as an appropriate foundation for developing *standards of excellence* for registries in support of an immunization program's core functions.

The term, *standards of excellence* was chosen because these standards are seen as ones to which all immunization programs and registries can strive; that is, they are more of a ceiling than a minimum set of requirements or floor. Thus, *standards of excellence* can be seen as comparable to best practices.

The standards are very concrete and tangible. Concrete standards should make it easier for projects to write registry enhancements into their grant applications, and also to help

to identify desirable registry features as part of an upgrade or replacement of their current application.

These standards are seen as a companion to the IPOM, the minimum registry functions developed by NVAC, and the new voluntary registry certification process developed by the CDC and the recent Technical Working Group (TWG). Together, these four sources are critical and complementary resources in developing a highly functional, flexible, and effective immunization registry. This is true regardless of whether your registry is city, county, regional or statewide in scope.

Your state laws governing uses of immunization, medical, and vital record information will of course affect to what extent you can implement some of these standards. Lastly, it should be acknowledged that a closer working relationship between registries and other immunization program functions might introduce natural tensions related to how the registry is used or in resource allocations. For instance, VFC staff may come to see the registry as a potential tool for ensuring compliance with VFC ordering and reporting. Such a use, however, may be at odds with the registry's marketing strategy of "selling" the registry to providers as a cost-beneficial service. Such tensions should be seen as the natural product of equally important programmatic goals, and as such can only be resolved within each program.

Self-Assessment Worksheets

The PROW *standards of excellence* includes a self-assessment tool, that registries can use to quickly review where they currently are in terms of the standards—where they meet or exceed the standards, and where additional resources could be focused to help them move toward reaching the standards.

The worksheets and instructions can be found in Attachment B.

Linking the PROW Standards to Other Assessments of Registry Activity and Performance

WHY LINK?

Since the *Standards of Excellence* are emerging at the same time as the CDC registry certification process is being piloted and finalized, the question naturally arises whether linking the two standards makes sense. The annual 317 grant application and the annual project/registry reports are also logical connections to make.

Generally speaking, the advantages of linking the PROW *Standards of Excellence* with existing standards or reports is that it would help ensure the *Standards* are reviewed and acted upon; the risk being that they become just another requirement to fulfill.

AIRA'S RECOMMENDATION

The PROW Committee of AIRA recommends that CDC incorporate the Standards of Excellence *into the Annual Registry Report.*

The Committee believes this is the best linkage at this time because:

- the registry report already includes questions on the relationship of the registry to the rest of an immunization project;
- both the report and the *Standards* involve assessing current performance, with the *Standards* providing the additional value of highlighting how the registry can improve through future enhancements;
- the registry report is part of the annual grant report, so the connection between registries and the rest of an immunization project—key to the whole purpose of the *Standards*—is reinforced;
- review of and reporting on the *Standards* will be done annually across all 317-funded projects; and
- the registry certification process is still too new to know how it will evolve. It is also voluntary, so only those mature registries applying for certification will likely use the Standards. The Committee believes the *Standards* have a critical role to play in helping in shaping newer or otherwise less mature registries as well.

AIRA is available to assist the CDC with this incorporation through further development and piloting during the PROW Project implementation phase.

If CDC elects to link the PROW *Standards* to the certification process, AIRA recommends that only Level I activities be used for that purpose.

A summary of the PROW Committee's analysis leading to the recommendation can be found in Attachment A.

SECTION ONE
REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF VACCINE MANAGEMENT

Principle

Immunization registries provide users with information and functions that support proper storage and handling of vaccines, and can internally support management of the VFC program.

IPOM Activity Areas

2.1 Vaccine Ordering, Distribution and Storage Systems
2.2 Vaccine Accountability (Provider Level)

Level I Standards of Excellence

1. Use the registry to direct users to information on proper vaccine storage and handling procedures.
2. Incorporate messages about the importance of proper vaccine management into registry materials and training.

EXAMPLES
A registry can use its communication tools, such as hotlinks, URLs, newsletters, and other communications to point users to web-published or other information on vaccine management. Use of slogans such as, "The registry can help you determine which shots come next, but making sure the vaccine you give is viable is just as important." can be easily incorporated into print materials, training scripts and/or other materials, user manuals, the registry splash screen, etc. The frequency in which users access the registry will greatly exceed any other communication channel available to the immunization project. Vary the messages used in the splash screen to include such things as a "Tip of the Month," so that users are encouraged to read the educational messages.

Level II Standards of Excellence

1. Support a vaccine inventory feature capable of adjusting doses due to wastage or transfer.
2. Monitor lots due to expire to see if re-distribution will be necessary.
3. Generate a doses administered or other report(s) to support vaccine accountability activities.

4. Capture VFC eligibility status and generate annual reports (either at the project or provider level).
5. Allow providers to re-enroll in VFC on-line, with necessary practice profile data generated from the registry.
6. Improve the accuracy of VFC eligibility reports by age groups.
7. Use provider/clinic information in the registry as the basis for a provider alert/broadcast messaging capability. Periodically cross-match with the VFC database for accuracy.

EXAMPLES

This level of activity greatly enhances registry support of a VFC program by supporting better management of vaccine inventories and by generating VFC reports. For instance, standard #3 could include registry support of VFC Profile reporting or monitoring vaccine usage over time, preferably by funding source.

Capturing VFC eligibility for children can greatly simplify provider reporting each year, and even allow such reports to be generated at the project versus provider level. Such capture and reporting may be very helpful as VFC accountability requirements increase in the future.

The provider/clinic database within the registry could be a very useful crosscheck with the VFC database, each potentially improving the other's accuracy and completeness.

Level III Standards of Excellence

1. Incorporate a feature that alerts users to lots due to expire or already expired.
2. Incorporate a link to VACMAN for automated ordering as supplies become low.
3. Enable VFC providers to report lost doses directly from the registry.
4. Incorporate a call-back system for shots deferred due to vaccine shortages, "cold" or improperly maintained lots of vaccine, or for other reasons.
5. Use a link from the registry's main screen to direct users to a provider satisfaction survey on the VFC program.

EXAMPLES

These standards feature high-level customer service, providing value-added features to make the registry even more beneficial to users. But more importantly they enhance vaccine delivery and management.

Standard #1 assumes you have a vaccine inventory function in your registry, and then use an alert system to notify users when their inventories are running low or due to expire. Web-based registries can provide a direct link into VACMAN for ordering VFC vaccines through the project.

Standard #3 would enable reports, through a registry link or other means, of lost doses due to expiration, wastage, or a break in the cold chain. This could include the estimated dollar value of both VFC and private stock vaccines.

A call-back feature for re-administering improperly stored vaccines or for deferred shots due to shortages are most feasible with the type of automation that registries provide.

SECTION TWO
REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF PROVIDER QUALITY ASSURANCE

Principle

By enabling access to complete immunization records, immunization registries support providers in delivering age-appropriate and timely immunizations, and in reducing both under- and over-immunization.

IPOM Activity Areas

4.1 Provider education
4.2 Provider site visits
4.3 Perinatal Hepatitis B Prevention

Level I Standards of Excellence

1. Export to CASA or otherwise use registry data as part of AFIX visits.
2. Use registry data to highlight general or clinic-specific practice issues that can be incorporated into provider trainings, newsletters, or a "tip-of-the-month" web link.
3. Use the registry login or main screen to announce upcoming trainings or other educational events.
4. Provide easy links to information needed by providers, including VISs.
5. Send recall notices to providers for patients who are behind in their shots.

EXAMPLES

Practical aspects of the registry such as vaccine scheduling algorithms, vaccine inventory and usage reports, and reminder-recall functions can help providers improve their immunization practices and help the immunization project reach its Provider Quality Assurance and VFC goals. These registry functions can be used to help providers improve the immunization coverage levels of their patient/client population. The registry can link providers to information they need every day in their practices, such as the immunization schedules, printable versions of VISs, information on immunization laws, or information on vaccine safety.

Level II Standards of Excellence

1. Monitor trends in provider immunization practices.
2. Enable reminder notices to parents/patients when vaccines are due. The notices can be vaccine or age-specific.

3. Include the four-day grace period in your prediction algorithm, if adopted in your state/project, and only for dose validation purposes.
4. Highlight any invalid doses when displaying a patient's immunization history.
5. Use the registry login or home screen to convey new or urgent immunization messages and materials.
6. Use registry data to prioritize AFIX/VFC provider site visits, based on clinics with low coverage or problematic practice issues.
7. Enroll birthing facilities to capture HBV and HBIG given at birth.
8. Use the registry to track series completion of children born to hepatitis B surface antigen-positive mothers.
9. Include a "VIS date" field for provider's to document the version of the VIS they gave to the patient. Default to the most recent date, but include 2-3 older versions for historical purposes

EXAMPLES

The registry could provide information on such trends/issues as the uptake of new vaccines, compliance with deferral policies due to vaccine shortages, and the impact of shortages on coverage levels. A registry can use its report capabilities to ensure providers are deferring immunizations during vaccine shortages and can use those same types of reports to recall the children that need to be caught up once the shortage is over.

Highlighting invalid doses is a great educational tool for providers, and reinforces the importance of minimum intervals and ages.

Standard #5 highlights how a registry can be used in a timely way to disseminate provider education information, without doing expensive mailings or waiting for the next edition of your newsletter. Since providers come to the registry frequently, use it to get your message out!

Using the registry as the primary tool for tracking HBV series completion in high-risk families not only helps perinatal staff, but also ensures the immunization data is available to providers and health departments.

The VIS date feature will emphasize to providers to use the most recent VIS ("If you're going to the picklist for an older version, chances are you're using an out of date VIS.")

Level III Standards of Excellence

1. Be able to display the reason for an invalid dose.
2. Run clinic-specific VFC reports at the project level, providing a copy of the report and any feedback to the clinic, as a part of a AFIX, VFC, or other site visit.
3. Include HBV and HBIG data fields in the electronic birth record or other mechanism, transferring that data to the registry during vital record uploads.
4. Work with long-term care facilities to track influenza and pneumococcal coverage levels.

EXAMPLES

Being able to display the reason for marking a dose as invalid, by using a fly-over window or other means, is a great educational tool for users. It provides on-the-spot, real-life learning, and so supports your Provider Quality Assurance goals.

The other standards provide optimal support for provider quality assurance, assessment, VFC, and perinatal staff by providing timely coverage and other reports without doing expensive chart pulls or hospital/nursing home surveys. Such reports can also help your staff target pocket of needs or under-served groups for needed immunizations and outreach.

While many registries focus only on the pediatric population, your immunization project also has adult immunization goals that the registry could support. Recruiting long-term care facilities or geriatric providers enable tracking of pneumococcal vaccine. This will also support the facilities in meeting Medicare guidelines for vaccination.

SECTION THREE
REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF SERVICE DELIVERY

Principle

Immunization registries are an effective tool for identifying and reaching under-served populations, and for supporting the delivery of immunizations in a child's medical home.

IPOM Activity Areas

5.1 Underserved populations
5.2 Medical home promotion

Level I Standards of Excellence

1. Enable WIC to access the registry for assessing UTD status of WIC clients, particularly in clinics where immunizations are being offered.
2. Enable school access to the registry for assessing student compliance with immunization laws.
3. Use registry data to generate coverage reports for your public immunization clinics, identifying pockets of under-immunization, based on geography, race/ethnicity, payment source, or other factors.
4. Identify high-volume immunization providers not part of the VFC program, using the registry as an incentive for enrolling in VFC.

EXAMPLES
The registry can be the primary source of immunization histories for public clinics. The same can be true for schools and WIC where immunizations are provided on-site.

Level II Standards of Excellence

1. Use registry data to identify seriously immunization-delayed individuals so that outreach can be conducted.
2. Identify children without a medical home (e.g., many sources of shot data) and conduct/refer for outreach.
3. Be able to generate individual reminder notices on vaccines coming due by provider organization, county of residence or project/registry wide.

EXAMPLES

Using the registry to quickly generate reports of children 3 or more months behind schedule can help staff target their outreach efforts toward those most in need. Such targeting of resources is increasingly critical as coverage rates increase and the remaining populations are more and more challenging.

Level III Standards of Excellence

1. Use enrollment rosters from child care facilities to identify children not up to date.
2. Provide individual immunization reports to WIC based on a WIC-supplied roster of children coming in for certification\re-certification.
3. Recruit long term care facilities to the registry, tracking pneumococcal coverage levels and conducting education outreach to those with low levels.

EXAMPLES

Such secure exchanges of batch electronic roster files can efficiently provide UTD status reports for WIC, schools, and larger childcare facilities.

Including nursing homes or other long-term care facilities is a way to increase adult immunization activities in the service delivery, provider quality assurance, and assessment areas. It also helps facilities comply with Medicare vaccine coverage requirements.

SECTION FOUR
REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF CONSUMER INFORMATION

Principle

Immunization registries are a source of credible immunization information and official immunization records.

IPOM Activity Areas

6.1 Information Development and Dissemination
6.2 Vaccine Benefit and Risk Communication

Level I Standards of Excellence

1. Generate official immunization records for consumer use.
2. Use registry notification or promotional materials to include general immunization information.

EXAMPLES
A registry can support consumer education efforts by making it easier for providers to print immunization records for patients.

Registry promotional or notification materials can also include brief information on immunizations, such as the importance of immunizations, where to go for shots, the VFC program, and school/childcare law. Such value-added features for consumers helps to strengthen the ties between the registry and the rest of the immunization program.

Level II Standards of Excellence

1. Generate or link to a variety of consumer education materials including Vaccine Information Statements and CDC Question/Answer sheets.

EXAMPLES
Providing links or URLs to sites such as the project's general immunization page, the NIP site, or the Immunization Action Coalition encourages and enables providers to distribute consumer education materials that address risk-benefit and other questions that today's parents/patients have. This capability ensures provider-distributed

information is accurate, current and appropriate—a particularly important capability given public concern over vaccine safety and other issues that make effective consumer education more important than ever. It also provides more visibility for the program's consumer education efforts.

Level III Standards of Excellence

1. Provide secure, direct (on-line) consumer access to immunization records for school or other enrollment purposes with appropriate security, privacy and confidentiality safeguards.
2. Disseminate consumer alerts through the registry to inform the public of important events such as outbreaks, free vaccine clinics, new vaccines, etc.
3. Send parents or guardians electronic reminder notices with the appropriate VIS(s) attached.

EXAMPLES

Since direct consumer access is most feasible with web-based registries, the main page could include information or links on a wide variety of topics of interest to consumers.

Using e-mail for reminder-recall notices presents the challenge of maintaining accurate e-mail addresses in the registry but has the advantage of enabling VISs to be sent directly to patients prior to the appointment.

***NOTE:** Allowing direct consumer access to registry data is controversial for a variety of security and confidentiality reasons. If you proceed with such access, most registry directors believe is most appropriate to not print any demographic, SSN, or provider information on records for consumer use. All such information is already known by the consumer and could be misused by others.*

SECTION FIVE
REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF SURVEILLANCE

Principle

Immunization registries support the reporting and investigation of vaccine-preventable diseases.

IPOM Activity Areas

7.1 Disease Surveillance and Response
7.2 VPD Reporting
7.3 Perinatal Hepatitis B Screening
7.4 Vaccine Safety

Level I Standards of Excellence

1. Provide immunization histories to disease investigators.
2. Enable disease investigators to add immunization histories not already in the registry.

EXAMPLES

Using the registry is critical to supplementing disease surveillance and response activities. Registries can also serve as the primary source of immunization histories when conducting vaccine-preventable disease outbreaks. The investigator should either access directly or request assistance in retrieving immunization histories from the registry on all suspecs or probable cases of vaccine-preventable disease.

For example, when investigating a suspected case of measles in an immunized child in a childcare facility, the investigator could access the registry for immunization histories of all children who attended the facility during the child's period of communicability. Such access actually helps to protect client confidentiality, since the investigator will not be combing through the entire medical records of numerous individuals.

Level II Standards of Excellence

1. Track adverse events in the registry.
2. Show which providers gave shots at what time, in case further medical record follow-up is required by investigators.

3. Have associations from the registry application to public health information systems and vice versa with appropriate privacy and confidentiality safeguards.
4. Provide a link to CDC's VAERS application.

EXAMPLES

Enabling providers to enter adverse events directly into the registry both helps the project in its adverse event surveillance efforts and provides valuable clinical information for other providers seeing that individual.

The registry can be the primary source for complete immunization histories of known, close or household contacts to a probable case, as well as information on the immunization provider. The rapid determination of susceptibility of contacts will enable the investigator to make a timely, clear and decisive assessment of immunization status when determining who will need vaccine or immune globulin during an investigation.

The registry should have electronic links to the National Electronic Disease Surveillance System (NEDSS) application. This would allow the system to be seamless to the user of both systems. The linkage to NEDSS would be critical to obtaining and the reporting of disease outbreaks to local, state and federal health officials in a timely manner.

Vaccine safety has been and will continue to be a challenge to immunization programs due to the increasing concerns raised by groups that question vaccine efficacy and safety. Information compiled in registries should be crosschecked against the state Adverse Event Reporting System (VAERS) per local policy. All unreported events following immunization should be reported to the national VAERS program. This would facilitate the collection of possible events which otherwise may go unreported to VAERS.

Level III Standards of Excellence

1. Create a common portal through which providers authenticate and then access the registry, NEDSS or other electronic communicable disease reporting system, and other public health applications.

EXAMPLES

Since private providers can be frustrated by the categorical and often uncoordinated programs within a health department, the registry can lead or be part of an effort to create a single web link to all secure applications designed for provider use. When logging in, the user would only have to authenticate once, then be allowed through the portal to access whichever applications they have rights to.

SECTION SIX
REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF ASSESSMENT

Principle

Immunization registries are a primary source of accurate assessment data on children and adults.

IPOM Activity Areas

8.1 General Population Assessments
8.2 Special Population Assessments

Level I Standards of Excellence

1. Use registry data to generate coverage and exemption rates on behalf of schools, or to validate reports that schools must submit as part of your state school immunization law.
2. Use registry data to generate coverage and exemption rates for childcare facilities or to validate their submitted reports.
3. Use registry data to conduct, supplement, or verify population coverage and exemption rates.
4. Generate reports, or export data to CASA, to identify geographic or demographic pockets of under-immunization.

EXAMPLES

The painstaking and labor intensive process to review and submit immunizations reports by child care facilities and schools can be lessened considerably by using the registry as a tool. The registry application may have a field for school filled by providers and/or schools, or schools may look up each student individually or submit an electronic roster to the registry. In either case, school personnel can effectively track and remind students of vaccinations required to remain enrolled. This also applies to childcare facilities.

A registry can also produce any immunization reports required by state law or regulation. These features could save considerable staff time within a program as well, or at least shift the burden from program to mid-level IT staff.

Registry data can be queried by geographical areas, or exported to CASA, to determine trend coverage rates for various geopolitical/geographic areas. The information can then be used to target resources, outreach, provider quality assurance, and other efforts. It may also trigger other assessment activities, such as parent barrier or provider knowledge-attitude-practice surveys.

Level II Standards of Excellence

1. Use registry data for adult immunization assessment.
2. Enroll nursing homes and long term care facilities as registry users, so adult pneumococcal coverage levels can be assessed.
3. Assess coverage levels among WIC participants. Allow WIC access to the registry for certification/recertification visits.
4. Provide registry access to Medicaid and to managed care organizations.
5. Use the registry for tracking vaccines given for occupational reasons.

EXAMPLES

Emphasis on adult immunization is growing. Registry data can be used for assessing coverage levels of all age groups, eliminating the need for estimates through tools such as the Behavioral Risk Factor Surveillance System. Additionally it can be used for recall and reminder of any age range, for all or specific vaccines.

Tracking pneumococcal vaccination can be particularly beneficial, given the number of physicians and facilities a typical elderly person visits or is admitted to. An 85-year-old nursing home resident for example, could have received a pneumococcal vaccination at 65 and have that documentation be buried in a medical file with 20 years of other medical documentation. This can also help a Medicare agency in assessing nursing home compliance with pneumococcal vaccination of residents.

Registries can interface with existing software, such as CASA, to determine trend coverage rates by clinic/organization or geographical area.

Registry data can be shared with - or the registry directly queried by, - WIC to support their immunization assessment requirement. This also helps the program in meeting recommendations around WIC-immunization linkage.

Medicaid and Managed Care will benefit by having access to the registry, as allowed by law, for their own quality assurance and assessment studies, such as HEDIS. Depending upon the maturity of the registry in terms of saturation, only some of the data needed for HEDIS may be available. But it sets the stage for using the registry as a reliable source of data, and hopefully as a program they will want to invest in!

Level III Standards of Excellence

1. Provide Geographic Information System (GIS) capability to monitor immunization trends in specific populations or geographic areas.
2. Assess Hepatitis B coverage at STD, HIV, correctional, or other high-risk settings.
3. Assess Hepatitis B coverage among various races.

EXAMPLES

It is estimated that one half of the reported Hepatitis B cases are patients who were seen or treated for a sexually transmitted disease or were incarcerated prior to the illness. Registry access at these institutions could provide immunization status and recommendation along with the ability to track and recall, to ensure series completion.

Data suggests a high rate of Hepatitis B infection in the Asian and African-American populations. To reduce the transmission of the disease, a high immunization rate must be maintained. The registry can be used to track, recall and analyze disparities in vaccine coverage for high-risk race and ethnic population per geographical location. This will require uploading race and ethnic fields from birth record loads and from other reliable sources such as Medicaid or schools as allowed by law.

GIS data can graphically display registry data in ways that could help with assessment, provider quality assurance, and allow staff to more effectively target their efforts.

Attachment Section

A. The Analysis Behind AIRA's Recommendation
B. PROW Standards of Excellence Worksheets Instruction and Standards of Excellence Worksheets
C. Registry Mentor Resource Group Recommendation
D. PROW Project Implementation Recommendation
E. PROW Survey Report
F. PROW Focus Group Report

Attachment A
The Analysis Behind AIRA's Recommendation

Below are possible advantages and disadvantages for the potential linkages the PROW Committee used in making its final recommendation to link the *Standards* to the annual registry report.

Linking to Registry Certification

Background: The CDC, through its Technical Working Group, has recently completed development of a voluntary registry certification process, whereby a registry is rated on its adherence to standards based on the twelve minimum functions established by CDC with considerable project input, and later approved by NVAC. The certification standards are thus a "floor" for determining minimum functionality and policies. The certification process involves a 2-3 day site visit to the registry, as well as to registry users. During the site visit, registry staff must demonstrate a wide variety of registry functionality. Because the *Standards of Excellence* represent more of a "ceiling" than a "floor," any linkage between the two could probably only be at Level I—the most basic level—of the *Standards.*

Advantages to Linking

- Increased visibility and credibility for the *Standards of Excellence.*
- Added value for the certification process, while also helping to accelerate programmatic and technical achievements in registries as they prepare for certification.
- Certification would provide an objective and unbiased review of the *Standards*.

Disadvantages to Linking

- Review of the *standards* would be voluntary, and likely only pursued by those highly mature registries that were ready for certification. This would leave out the majority of registries that could benefit from the concrete ideas for improvement found in the *Standards.*
- Only Level I would likely be linked with certification, potentially leaving Levels II and II as orphans, when in fact they are the most likely to advance the state of registry development.

Linking to the 317 Grant Application

Advantages to Linking

- Both are planning processes.
- The *Standards* can help identify desired registry enhancements, which could then go into the grant application and budget.

- The *Standards* are based on the Immunization Program Operations Manual (IPOM), CDC's guidance for a 317-funded immunization program, so the *Standards* could help a project meet overall CDC grant requirements.
- Increased visibility and credibility for the *Standards.*
- Review of the *Standards* would be an annual process.

Disadvantages to Linking

- Review of the *Standards* could easily become "just another requirement" versus a thoughtful self-assessment process.

Linking to the Annual Registry Report

Advantages to Linking

- Review of the *Standards* would be an annual process.
- Increased visibility and credibility for the *Standards.*
- The registry report is a measurement of current performance; the *Standards* both an assessment of current and future performance (i.e., enhancements).

Disadvantages to Linking

- Review of the *Standards* could easily become "just another requirement" versus a thoughtful self-assessment process.

No Linkages/Completely Voluntary

Advantages

- More likely the *Standards* will be used well, since anyone using them will have *chosen* to do so.
- Matches the voluntary nature of the certification process.

Disadvantages

- Potential loss of visibility and credibility

Attachment B
PROW *Standards of Excellence* Worksheets Instructions

The following worksheets are designed as a self-assessment tool to assist you in identifying where you currently are in terms of the standards—where you meet or exceed the standards, and where additional resources could be focused to help you move toward reaching the standards.

The labels used in the worksheets are defined as follows:

Level	Levels I, II, and III represent a rank ordering of activities from relatively easy to implement (I) to moderately advanced (II) to more challenging or resource-intensive (III).
IPOM Activity Area	The broad activity areas covered in the relevant chapter of the CDC *Immunization Program Operations Manual.* These are listed as a cross-reference for the user.
Fully Meet	The immunization project has fully implemented and possibly gone beyond this standard in its entirety. The actual activity may differ somewhat from how it is described in the standard but the intent is the same.
Partially Meet	The standard is in the process of being implemented or is implemented in part.
Could Meet	The standard could be implemented with low to moderate resource investment, such as new programming, changes in policies and procedures, or changes in application features. Implementing this standard could be accomplished within the next year or two.
Cannot Meet	This standard would take a prohibitive amount of resource investment to implement, and cannot be considered at this time.
No Plan to Meet	The registry or immunization project does not see this standard as a priority, and does not intend to implement it for the foreseeable future.

In using the tool, a project could simply check the most appropriate box for each standard, or instead use numbers in the boxes to not only reflect current status but level of priority as well.

REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF

Vaccine Management

IPOM Activity Areas:
2.1 Vaccine Ordering, Distribution and Storage Systems
2.2 Vaccine Accountability (Provider Level)

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
I	Use the registry to direct users to information on proper vaccine storage and handling procedures.	2.1.0 2.1.7						
	Incorporate messages about the importance of proper vaccine management into registry training and materials.	2.1.0 2.1.7						
II	Support a vaccine inventory feature capable of adjusting doses.	2.1.0						
	Monitor lots due to expire to see if re-distribution will be necessary.	2.1.0						
	Generate a doses administered or other report(s) to support vaccine accountability activities.	2.2.7 2.2.3 4.2.3						
	Capture VFC eligibility status and generate annual reports (either at the project or provider level).	2.2.5						
	Allow providers to re-enroll in VFC on-line, with necessary practice profile data generated from the registry.	2.1 2.2.5						
	Improve the accuracy of VFC eligibility reports by age groups.	2.2.5						
	Use provider/clinic information in the registry as the basis for a provider alert/broadcast messaging capability.	2.1 2.2 4.1						
III	Alert users to lots due to expire or already expired	2.1.0						
	Link to VACMAN for automated ordering as supplies become low.	2.2.2						

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
III	Enable VFC Providers to report lost doses directly from the registry.	2.2.10						
	Incorporate a call-back system for shots deferred due to vaccine shortages or other reasons.	2.1.0						
	Use a link from the registry to direct users to a VAC provider satisfaction survey.	2.2.8						

REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF

Provider Quality Assurance

IPOM Activity Areas:
4.1 Provider education
4.2 Provider site visits
4.3 Perinatal Hepatitis B Prevention

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
I	Use registry data as part of AFIX visits.							
	Use registry data to highlight general or clinic-specific practice issues that can be incorporated into provider education.	4.2.9 4.2.12						
	Use the registry login or main screen to announce upcoming trainings or other educational events.	4.1						
	Provide easy links to information needed by providers.	4.1						
	Send recall notices to providers on patients who are behind in their shots.	4.2.19						
II	Monitor trends in immunization practice, particularly assessing the uptake of new vaccines, compliance with deferral policies due to vaccine shortages, and the impact of shortages on coverage levels.							
	Send reminder notices to parents/patients when vaccines are due. The notices can be vaccine- or age-specific.	4.2.19						
	Include the four-day grace in your prediction algorithm, if adopted in your state/project, for dose validation purposes only.							
	Highlight any invalid doses when displaying a patient's immunization history.							

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
II	Use the registry log-in or home screen to convey new or urgent immunization messages and materials.	4.1.1 4.1.2						
	Use registry data to identify clinics with low coverage or practice issues as a way to prioritize AFIX/FVC provider site visits.	4.2.1 4.2.5 4.2.9						
	Enroll birthing facilities to capture HBV and HBIG given at birth.	4.3.5 4.3.6						
	Use the registry to track series completion of children born to hepatitis B surface antigen-positive mothers.	4.3.7 4.3.8 4.3.9 5.1.10						
III	Be able to display the reason for an invalid dose.							
	Include HBV and HBIG data fields in the electronic birth record or other mechanism, transferring that data to the registry during vital record uploads.	4.3.5 4.3.6						
	Work with long-term care facilities to track influenza and pneumococcal coverage levels.	4.2.10						

REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF

Service Delivery

IPOM Activity Areas:
5.1 Underserved populations
5.2 Medical home promotion

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
I	Enable WIC to access the registry for assessing UTD status of WIC clients.	5.1.5 5.1.8 5.1.13						
	Enable school access to the registry for assessing student compliance with immunization laws.	5.1.3 5.1.6						
	Use registry data to generate coverage reports for your public clinics.	5.1.11						
	Identify high-volume immunization providers not part of the VFC program.	5.2.5						
II	Use registry data to identify seriously delayed individuals so that outreach can be conducted.	5.1.16						
	Identify children without a medical home (e.g., many sources of shot data) and conduct/refer for outreach.	5.1.12 5.2.1						
	Be able to generate individual reminder notices on vaccines coming due by provider organization, county of residence, or project/registry wide.	5.1.14						
III	Use enrollment rosters from day care facilities to identify children not UTD.	5.1.7						
	Provide individual immunization reports to WIC based on a WIC-supplied roster of children.	5.1.5 5.1.8 5.1.13						
	Recruit long term care facilities to the registry, tracking influenza and pneumococcal coverage.	4.2.10						

REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF

Consumer Information

IPOM Activity Areas:
6.1 Information Development and Dissemination
6.2 Vaccine Benefit and Risk Communication

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
I	Generate official immunization records for consumer use.	6.1.2						
	Use registry notification or promotional materials to include general immunization information.	6.1.1						
II	Generate or link to a variety of consumer education materials including Vaccine Information Statements and CDC Question/Answer sheets.	6.1.1						
III	Provide secure, direct (on-line) consumer access to immunization records for school or other enrollment purposes with appropriate security, privacy and confidentiality safeguards.	6.1.1						
	Disseminate consumer alerts through the registry to inform the public of important events such as outbreaks, free vaccine clinics, new vaccines, etc.	6.1.1						
	Send parents or guardians electronic reminder notices with the appropriate VIS(s) attached.	5.1.14 6.1.1						

REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF

Surveillance

IPOM Activity Areas:
7.1 Disease Surveillance and Response
7.2 VPD Reporting
7.3 Perinatal Hepatitis B Screening
7.4 Vaccine Safety

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
I	Provide immunization histories to disease investigators.	7.1.2 7.1.5						
	Enable disease investigators to add immunization histories not already in the registry.							
II	Track adverse events in the registry.	7.4 7.4.3						
	Show which providers gave shots at what time, in case further medical record follow-up is required by investigators.	7.1.2						
	Have links from the registry application to the NEDSS or other communicable disease reporting system and vice versa with appropriate privacy and confidentiality safeguards.	7.1.2 7.1.5						
	Provide a link to CDC's VAERS application.	7.4.2						
III	Create a common portal through which providers authenticate and then access the registry, NEDSS or other electronic communicable disease reporting system, and other public health applications.							

REGISTRY STANDARDS OF EXCELLENCE IN SUPPORT OF

Assessment

IPOM Activity Areas:
7.1 Disease Surveillance and Response
7.2 VPD Reporting
7.3 Perinatal Hepatitis B Screening
7.4 Vaccine Safety

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
I	Use registry data to generate coverage and exemption rates for schools, or to validate reports schools submit as part of your school immunization law.	5.1.6 8.1.1						
	Use registry data to generate coverage and exemption rates for childcare facilities or to validate their submitted reports.	5.1.7 8.1.3						
	Use registry data to conduct, supplement, or verify population coverage and exemption rates.	8.1.2 8.1.4						
	Generate reports, or export data to CASA, to identify geographic or demographic pockets of under-immunization.	8.1.2 8.2.1						
II	Use registry data for adult immunization assessment.	8.1.4 8.2.5						
	Enroll nursing homes and long term care facilities, so adult pneumococcal coverage levels can be assessed.	8.2.5						
	Assess coverage levels among WIC participants. Allow WIC access to the registry for certification/re-certification visits.	8.2.4						
	Provide registry access to Medicaid and to managed care organizations.	8.2.4 8.2.7						
	Use the registry for tracking vaccines given for occupational reasons.							

Level	Standard of Excellence	IPOM Activity	Self-Assessment					Next Steps
			Fully Meet	Partially Meet	Could Meet	Cannot Meet	No Plan to Meet	
III	Provide Geographic Information System (GIS) capability to monitor immunization trends in specific populations or geographic areas.							
	Assess Hepatitis B coverage at STD, HIV, correctional, or other high-risk settings.	8.2.2						
	Assess Hepatitis B coverage among various races.	8.2.3						

Attachment C
AIRA/PROW Project

REGISTRY MENTOR RESOURCE GROUP

The AIRA/PROW Core Group discussed the formation of a registry mentor resource group consisting of registry developers who are willing to serve as mentors and agreed on the following:

1. **A registry mentor resource group would further the goal of linking registries and establishing a network for sharing ideas and "best practices".**

2. **Recommended areas of focus** include but are not limited to the following:
   - Private provider participation strategies and tools
   - Initial registry planning
   - Methods of using registry data for coverage assessments and trends
   - HL7 development
   - Methods of using registry data to support surveillance activities
   - Funding strategies
   - Integrating registries with other child health systems
   - Technical development: system security; communications; system architecture; web-based systems
   - Partnerships/advocacy
   - Legislation/Policy: consent, data sharing-inter and intra state
   - Privacy/confidentiality
   - Promotion/marketing of registries
   - Deduplication methods

3. **Recommended expectations and roles** for registry mentors include:
   - Regular conference call meetings to be determined by the group at its first meeting
   - Contributing to the 'best practices" archive to be established within the first year of PROW Project implementation
   - Contributing to the development of a resource toolkit for distribution and posting on the web site
   - Recruitment of additional mentors
   - Availability for consultation, technical assistance and/or problem solving via email and/or other agreed upon means of communication with registries seeking assistance in one or more of the focus areas
   - Reporting back to the mentor network on successes and challenges

4. **Recommended start-up:**
   It is recommended that the registry mentor resource group be established as part of the implementation phase of the PROW Project during year one so that by December 2003, a network of a minimum of 5-10 registries including a broad range of staff mentors that represent both front-line and managerial expertise/experience, will be in place.

Attachment D
AIRA/PROW Project Implementation

Implementation of the PROW Project will include the following:

- Formation of a PROW Implementation Team
- Development of an Implementation Plan by the PROW Team at a meeting to be scheduled during the CDC Immunization Program Managers Annual Meeting in 2003
- Preparation and submission of plan to CDC for approval
- Implementation of plan
- Monthly conference calls of the PROW Implementation Team
- Development of a PROW Standards of Excellence workshop for the 2003 Immunization Registry Conference
- Development of a Resource Toolkit that incorporates best practices

Attachment E
PROW Survey Report

I. BACKGROUND

The American Immunization Registry Association (AIRA) was contracted by CDC to coordinate a project to develop programmatic standards for immunization registries to support immunization program core functions. Key activities include:

- Survey development and administration
- Focus Group.
- Formation of the Programmatic Registry Operations Workgroup (PROW).
- Programmatic Registry Operations standards and best practices recommendations.
- Registry Mentor Resource Group formation.

AIRA is a membership organization founded in July 1999 to advocate for support of immunization registry development and sustainability. Its purpose is to be a resource for standards use and development, training, technical assistance and communication and information sharing. The organization also promotes and supports partnerships and collaborative work and sharing of collective knowledge and successes. Currently there are nearly 100 members representing public health, managed care, community coalitions, computer consultants and software and hardware vendors. It is funded through special project grants and membership dues. CDC, All Kids Count and Wyeth Pharmaceuticals are current funders of AIRA. AIRA has an elected Board of Directors and an Executive Director.

II. SURVEY PURPOSE

The purpose of the ***Survey on Immunization Registry Support of Immunization Programs*** was to assess current and potential programmatic registry activity and to identify best practice examples. The survey was also designed so that results would serve as one of the tools to inform the work of the PROW.

III. METHODOLOGY

All 73 Immunization Programs from the current CDC list were surveyed. Both Immunization Program Managers and Immunization Registry Managers at each site were asked to respond to the questionnaire. The survey was a web-based tool administered by the AIRA website administrator, WebWorks, Inc. A PDF format of the survey was distributed to the list via broadcast email with instructions on accessing and completing the survey on-line. Distribution of the survey occurred in December 2001. Analysis of responses occurred in January 2002 and a preliminary findings report was completed for presentation at the CDC Immunization Program

Managers Annual Meeting in Atlanta, GA on January 24, 2002. Overall the response rate was high with 70% of all projects surveyed submitting at least one response. *See attached Geographic Distribution of Responses.*

Survey Response Rate

- 70% (n=51) of all programs surveyed submitted at least one response.
- 88% (n=44) of state projects surveyed submitted at least one response.
- 50% (n=6) of city/county/regional projects surveyed submitted at least one response.
- Territories/DC/Puerto Rico/VI (n=1) one response to the survey received.

IV. KEY FINDINGS

- **70%** of Program and Registry Managers combined who responded to the survey rated the ***quality and functionality*** of registries as ***excellent or good***. Functions falling into this overall category and were rated excellent or good included: **security of database, confidentiality/privacy, ability to print immunization records and timely access to immunization data.**

Breakdown: Program Managers=58% Registry Managers=79%

- **48%** of Program and Registry Managers combined who responded to the survey indicated that their ***registry*** currently ***helps*** them ***to perform vaccine management functions more effectively.*** Vaccine management functions included vaccine inventory management and vaccine ordering (VACMAN).

Breakdown: Program Managers=41% Registry Managers=62%

An additional 20% of all respondents are considering implementing vaccine management functions.

- **41%** of Program and Registry Managers combined who responded to the survey indicated that ***in the area of Provider Quality Assurance their registry currently helps them to perform VFC eligibility and administration functions more effectively.***

Breakdown: Program Managers=40% Registry Managers=50%

An additional 25% of all respondents are considering implementing provider quality assurance functions.

- **29%** of all respondents indicated that their ***registry provides support for assuring effectiveness of overall service delivery functions that include school and day care surveys/information, reminder/ recall and WIC and Medicaid access.***

Breakdown: Program Managers=27% Registry Managers=36%

An additional 37% of all respondents are considering implementing these service delivery functions.

- **45%** of Program and Registry Managers combined who responded to the survey indicated that ***the registry provides support for surveillance functions that includes adverse events.*** **21%** of respondents ***are considering implementing surveillance functions.***

Breakdown: Program Managers=36% Registry Managers=55%

65% of respondents are participating or considering participating in the National Electronic Disease Surveillance Systems (NEDSS) project.

- **36%** of respondents indicated that their ***registry supports population assessment functions including identifying geographic or demographic pockets of need.***

Breakdown: Program Managers=38% Registry Managers=35%

An additional 35% of respondents are considering implementing population assessment functions.

- **There was strong agreement** between the Program and Registry Managers who responded to the survey on the question of ranking the **most useful areas for registries to support immunization programs. Most useful areas included: coverage assessments, reminder/recall and provider visits-AFIX.**

- **Program and Registry Managers** responding to the survey **agreed** that **vaccine management, VFC eligibility, disease control and case management functions were moderately useful areas for registries to support immunization programs.**

- **29%** of respondents indicated that their ***registry is using, integrating or linking with other child screening, preventive health services*** including lead screening, newborn genetic screening, newborn hearing screening and asthma.

Breakdown: Program Managers=23% Registry Managers=36%

An additional 6% of respondents are considering integrating their registries.

- **79%** of all respondents are **collecting or considering collecting adult immunizations and 82% expect to use their registries in future bio-terrorism activities.**

V. CHALLENGES

- **26%** of all Program and Registry Managers who responded **identified** a number of issues that present **challenges** to more effective use of Immunization Registries by Immunization Programs. **Key issues** identified included: ***clarity on registry functions; organizational structure and/or communication issues; relationship with Medicaid; funding issues; data quality; private provider participation; technical support and privacy/confidentiality issues.*** **32%** of respondents were ***neutral*** on the issue of these challenges. This has been interpreted as an indication that these respondents feel these challenges are not obstacles to using their registry.

Challenges:	**Program Managers=35%**	**Registry Managers=31%**
Neutral:	**Program Managers=33%**	**Registry Managers=30%**

- **32*% of respondents felt that using the registry to help them perform vaccine management functions more effectively was a challenge especially in the *areas of ordering vaccines, managing vaccine inventories and documentation of expired doses.***

Breakdown:	**Program Managers=41%**	**Registry Managers=21%**

- **34%** of respondents felt that the area of ***Provider Quality Assurance presents a challenge particularly related to VFC eligibility and validating public clinic VFC profiles.***

Breakdown:	**Program Managers=37%**	**Registry Managers=25%**

- **35%** of respondents indicated **that use of the registry to support effectiveness of overall service delivery functions was a challenge**. ***High challenge areas included: school and day care surveys to identify children not up to date, Medicaid and WIC access and identifying medical homes of persons receiving immunizations in public clinics for future immunization referrals.***

Breakdown:	**Program Managers=41%**	**Registry Managers=30%**

- **34%** of respondents ***do not use their registry to support surveillance functions.***

Breakdown:	**Program Managers=44%**	**Registry Managers=27%**

- **32%** of the respondents **do not use their registry for support with population assessments especially** ***in the areas of assessment of immunization coverage rates among target children and use of registry data on influenza and pneumococcal coverage levels.***

Breakdown: Program Managers=44% Registry Managers=30%

- **Integrating** registry services with other child health services **is an identified challenge**. **63%** of all respondents **answered no to the question about service linking and/or integration** related to their registry**.**

Breakdown: Program Managers=68% Registry Managers=60%

- **36%** of all respondents identified **responding to vaccine safety issues** especially in the areas of **VAERS and CISA** participation as a challenge.

Breakdown: Program Managers=35% Registry Managers=37%

VI. BEST PRACTICE HIGHLIGHTS

The survey asked respondents about ***current use of the registry in bioterrorism events and current use of the registry that improves, enhances and/or streamlines an immunization program activity.*** The following responses highlight current activities in each of these question categories.

CURRENT USE OF REGISTRY IN BIOTERRORISM EVENTS

- **Arizona:** Queried the system for people who may have received anthrax vaccine and prepared the system to add a tracking system for antibiotics (Cipro).
- **Missouri**: Bioterrorism calls are logged into the system.
- **Washington**:We can track the administration of vaccines such as anthrax and smallpox. This is the only aspect already in production that could be implemented if needed.

CURRENT USES OF THE REGISTRY THAT IMPROVES, ENHANCES AND/OR STREAMLINES AN IMMUNIZATION PROGRAM ACTIVITY

- **Alabama**: Used to create benchmark reports for VFC providers.
- **Arizona**: Use of GIS mapping to identify high rate/low immunization coverage level areas and use of this information to provide education and technical support to providers in these locations.
- **California**: CASA report for providers leads to improvement in coverage.
- **Connecticut**: Currently working with NIP on Prevnar vaccine efficacy study. Plan to use registry to do a study looking at breakthrough varicella cases. Currently monitor pneumococcal conjugate vaccine usage for VFC eligible population.
- **Delaware**: Registry is currently used to assist in identifying WIC children who need shots and reminder/recall letters.

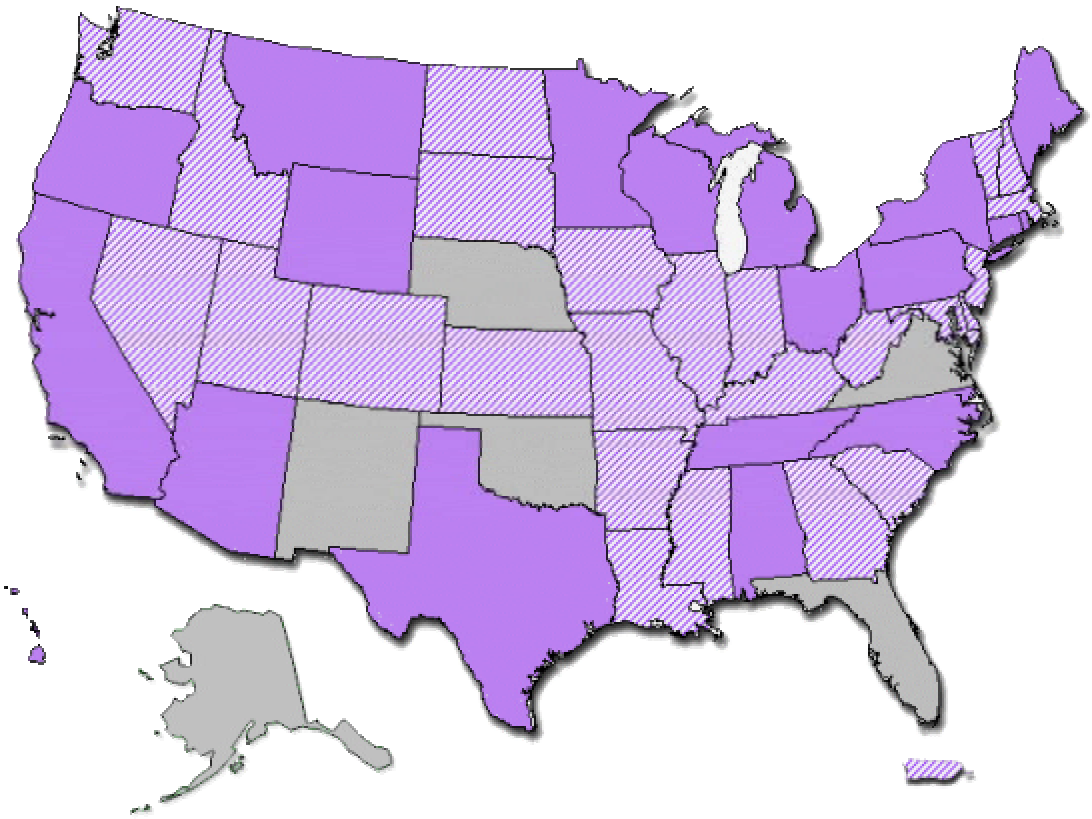
- **Illinois**: Through public data that is input via EDI, quarterly coverage level reports are generated for the WIC-Immunization initiative mandated by DHS/WIC program.
- **Maine**: Reporting of patient VFC information for practices. Monitoring of vaccine balances and redirection of inventory affected by vaccine shortages.
- **Michigan**: Michigan is a sentinel site participant. We monitor population base immunization levels for health jurisdictions, county and statewide coverage using registry data. We also use the registry to help identify pockets of need, patterns in vaccine usage and uptake of new vaccines.
- **Minnesota:** We do quality checks on all data before it is added to the registry and do a 200 chart review to confirm accuracy and completeness before any provider joins our registry. They must pass the audit with 90% accuracy and 80% completeness. Most pass the first time but there are generally improvements needed such as: using vaccine only for ages licensed, updating charting and billing for OPV/IPV, PCV7, charting correctly for DT and TD, etc. Every time a new vaccine comes out we help clinics update their charting and billing practices. The registry supports the immunization program functions including provider feedback/quality improvement, assessment, vaccine management, VFC operations and case management.
- **Montana:** Provider coverage assessment and vaccine inventory management are supported by the registry. We are also beginning to use the registry to assess the immunization rates of public providers prior to clinic evaluations/visits.
- **North Carolina**: Accountability for local health departments. Data from the NCIR is used to provide CASA-ready files to local Health Departments on a regular basis for use in tracking. Annual compliance assessments of LHDs are done using NCIR data replacing manual chart audits.
- **New Hampshire**: More accurate accounting of vaccine usage and vaccine waste. Reduces administration of invalid doses.
- **New Jersey**: Perinatal Hepatitis B case management.
- **Nevada:** Enhances and improves the efficiency of reminder/recall, doses administered reporting and vaccine algorithms that determine needed vaccines.
- **New York City:** Communication with childhood immunization providers for broadcast faxing and access to an informational web site. Communication with parents through distribution of printed materials promoting both immunization and use of the registry to obtain child records. The registry is also used to assist the assessment team in identifying the patients of private physicians to assist with the chart pulls. Assessment teams encourage physicians to use the registry and also check to see if they are reporting to the registry. They inform the registry provider relations staff of their findings for follow up. The registry is also used to monitor pneumococcal vaccine uptake.
- **Ohio**: We have used the registry to assess what features/functions health care providers use. This enables us to make changes to improve the flow and function of the registry.
- **Oregon:** Registry is used to monitor the impact of changes in the vaccine schedule.

- **Philadelphia**: Reported on Rotavirus Vaccine given in Philadelphia so that providers could follow up with their patients. KIDS can report on Prevnar and Varicella uptake, and with varicella we have reported on coverage rates within specific geographic areas of Philadelphia.
- **Rhode Island**: Registry is used to identify inappropriate vaccine use and to monitor the use of new vaccines or schedule changes. It is also used to monitor doses administered and identifying vaccinated children in outbreak areas.
- **Tennessee:** The SIIS is involved in PCV7 use studies and studying schedule reductions. Target children at high risk of non-completion of immunization series.
- **Texas:** Registry is used to monitor the impact of vaccine issues with usage (e.g. HepB vaccine at birth and preservative used in vaccine; MMR press regarding autism). SAIRS is currently sharing data with CDC and Texas Department of Health for individual/series vaccine tracking and accountability. SAIRS is available for all public clinics and all VFC providers in addition to other 3rd party immunization partners/providers.

V. SUMMARY

- The status of immunization registries based on all respondents to the survey indicates that 66% are population-based registries, 10 % are non-population based and 24% are in the development phase. 24% of the programs surveyed have submitted, and/or have approved Medicaid APDs, and 23% are planning on submitting an APD. Of the programs surveyed, 62.5% of the registries are under direct management of the immunization program, 25% are somewhat a part of the immunization program and 12.5% are not organizationally aligned with the immunization program.
- Immunization Programs currently use registries to support core functions and there is interest in expanding this use.
- There appears to be strong agreement between Immunization Program Managers and Immunization Registry Managers regarding the most useful areas for registries to support immunization programs.
- Registries are improving immunization program effectiveness through assessing coverage levels, and increasing vaccine accountability and management.
- There is high interest in using registries in future bioterrorism related activities.

Geographic Distribution of Responses



States with both manager and program manager responding registry

States with one respondent

Did not respond

List of non-statewide sites:

MN – Immulink

NV – VAX

NY – Citywide Immunization Registry

NY – Central New York Immunization Registry

PA – Philadelphia Kids Immunization Database Tracking System

TX – San Antonio Immunization Registry System

Attachment F
PROW Focus Group Report
Immunization Program Needs & the Role of Immunization Registries

I. PURPOSE

As part of the deliverables for the AIRA/CDC/PROW (Programmatic Registry Operations Workgroup) Project, a focus group was held on Friday, January 25, 2002 in Atlanta at the Immunization Program Managers Annual Meeting. The purpose of the group was to discuss key findings of the PROW Survey on ***Immunization Registry Support of Immunization Programs*** and to seek input on the PROW Project. The outcomes from the focus group will provide additional data for the work of the PROW who will be charged with the planning and development of registry programmatic standards to support immunization program core functions.

II. FORMAT

The focus group was a one hour and forty-five minute session. It was co-facilitated by Sue Salkowitz, Consultant and AIRA Board member and Cindy Sutliff, AIRA Executive Director**.** The format was designed to be informal and interactive and included the following:

- Opening: Group Introductions
- Introduction: Purpose of Focus Group
- Transition: Questions that Frame Key Areas
- Key Questions: Questions designed to get insight into key issues
- Ending: Brings closure to discussion.
- Summary: Identifies common themes; notes different views; things not mentioned. Includes a final question and thanks.

III. QUESTIONS

The focus group used a series of questions that were designed to expand on the information gathered from the PROW survey and to get a sense from the group regarding the concept of programmatic registry standards. There were three main transition questions and 10 key questions. The entire questioning period was recorded to assist in the final analysis.

(See attached list of Focus Group Questions)

IV. KEY FINDINGS

Registry Functions

- Although survey responses indicated that there was uncertainty regarding ***registry functions***, focus group participants indicated that basic registry functions are clear to immunization program managers. Responses on the survey may have been a result of how the question was phrased.

- Focus group participants identified prioritization as an issue. Funding issues often create a "pull" on registry priorities.

- Respondents did not rank **vaccine safety** in the top five on the survey, as a function that they felt immunization registries would be helpful in supporting. Focus group participants felt that registries should have the ability within the system to support vaccine safety core functions citing again that perhaps the phrasing of the question may have resulted in the survey outcome. Some issues they identified related to vaccine safety included provider reporting of manufacturer and lot number data, legal issues in some states about how records are classified and the recording of adverse events.

- Using immunization registries in supporting immunization program **provider and consumer education** core functions appeared to be a low priority based on the survey responses. Focus group participants felt that web-based registry systems are effective in provider education. Those registries that are moving toward a Web-based system also expressed hope for high usage by school nurses and day care providers. Other ways of supporting consumer communication/education cited included broadcast fax capability. WIC access/integration was cited as working in some registries and as an issue for others.

- The survey results indicated a high percentage of registries currently collect data on adult immunizations. Although few registries were used during the recent **bioterrorism** activities following the September 11, 2001 terrorist attacks, respondents to the survey indicated that they expected to use their registry in future bioterrorism activities if required. Focus group participants were supportive of incorporating registries into their **bioterrorism preparedness** plans and submissions for grant funding and for having registries become a part of the larger, integrated public health information system.

PROW Project

- Developing and recommending programmatic registry operations standards to the CDC is a key activity of the Programmatic Registry Operations Workgroup (PROW). Focus group participants in general were supportive of this initiative citing, however, that programmatic standards should have a low threshold for meeting minimum requirements so that all registries, no matter what stage of development they are at, have the opportunity to reach those goals.

- Utilizing a "lessons learned" model via a specific Web page on a designated Web site that would also allow for information exchange and the testing of different systems/models was cited by the participants as something that would be helpful and would add to the success of the initiative. Creating a mentor (peer-to-peer) support group was another suggestion for ways to increase the success of the project.

- Advantages to the PROW initiative were seen as a way to build capacity within registries, increase communication between registries and immunization programs, more productively establish collaboration with private providers and create a model for collecting and sharing best practices that continue to support and give credence to the benefits of registries.

- Issues as opposed to disadvantages that were raised included finding a way to rate/evaluate the standards. Participants raised the question: What happens if programmatic standards are not met?

V. CONCLUSIONS

- Programmatic registry operations standards will be useful in improving registry capacity and enhancing the overall effectiveness of immunization programs.

- Guidelines for assessment/evaluation of the standards should reflect a simple self-assessment, goal-setting model that might also incorporate a peer-to-peer evaluation process.

- Best practices should be used to provide models of "lessons learned" and to promote replication.

- Integrating registries into the larger public health information infrastructure is a desirable outcome.

FOCUS GROUP
January 25, 2002

Immunization Program Needs and the Role of Immunization Registries
Conducted by: The American Immunization Registry Association

QUESTIONS

Opening: **10 min**

1. Tell us your name.

2. **Introduction:** **5 min**

3.

The purpose of the focus group is for us to further discuss the key findings of the survey on ***Immunization Registry Support of Immunization Programs*** and to seek your input on the Programmatic Registry Operations Workgroup (PROW) project. (Show slide # one of Amy's presentation again for project background and project activity review).
Information from this focus group will be used to inform the work of the PROW.

Transition: **20 min**

- **As Program Manager what do you expect from your registry?**
- **What are you currently getting?**
- **What do you want to get in the future?**

Key Questions: **40 min**

1. 68% of all responses on the survey indicated that ***registry functions were not clear.*** When you hear "immunization registry" what comes to mind?
2. The survey asked you to rank the core functions that you feel Immunization Registries would be most helpful in supporting. The functions that emerged as most useful to you were:

    - Reminder/Recall
    - Coverage Assessments
    - Provider visits-AFIX

    Vaccine safety was NOT ranked as a priority. Do you see a role for the immunization registry in supporting this function? What activities do you see registries doing?
3. Consumer and provider education were barely mentioned. Should they have been? How could the immunization registry be used to help in your program provider and consumer education function?
4. How else would you like to be helped by the immunization registry?

5. What changes are necessary for your program to be able to get this type of support from the immunization registry?

Ending: **20 min**

1. One of the key activities of the PROW is to recommend programmatic registry operations standards to the CDC. Do you see a need for programmatic operations standards for registries?
2. What do you see as the advantages/positive aspects of the PROW project?
3. What do you see as the disadvantages/negative aspects of the PROW project?
4. For the PROW project to be successful what do you think needs to happen?
5. Would you be interested in participating on the PROW?

Summary: **5 min**

Summarize common themes, different views from the discussion.

Final Question: Think about what we discussed today. Have we missed anything?

Thank you.